Understanding Patient Values for Prevention and Treatment

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Introduction

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Goals

- Review approaches to the conceptualization and measurement of patient values and preferences
- Discuss qualitative strategies for refining conceptual models of patient treatment preferences and health outcomes
- Examine in depth one group of methods for measuring preferences: Stated choice including conjoint analysis
- Consider psychometric analyses for evaluating the characteristics of measures of values and preferences
Agenda

- Consideration of constructs and measures
- Description of qualitative methods to develop measures
- Examination in depth of one measurement method
- Discussion of establishing evidence on measurement characteristics
Constructs and Measurement Methods

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Consensus on Significance

- International Patient Decision Aid Standards (IPDAS) Collaboration Recommendations on Values
  - Describe procedures and outcomes to help patients imagine what it is like to experience their physical, emotional, and social effects
  - Ask patients to consider which positive and negative features matter most
  - Suggest ways for patients to share what matters most with others.
What are preferences?

- Valuation of health care goods, services, and interventions

- Economic Theory and Behavioral Decision Theory
  - Maximize subjective expected utility
  - Utilities can be scaled in dollar-equivalence terms
  - Based on assumptions of consistency and rationality with some limits
Preferences or Values

- Preferences
  - Economic theory
  - Utilities

- Values
  - Psychological theory
  - Attitudes, preferences, interests, goals, needs
Preferences or Health Status

- **Health Status**
  - Patient experience, well-being, function
  - Concurrent or retrospective

- **Preferences**
  - Patient, consumer, or societal values and goals
  - Prospective
Economic Model

Preferences

Information

Utility of Choice Alternatives

\[ U_1 = u(\text{Attrib}_{11}, \text{Attrib}_{12}, \ldots, \text{Attrib}_{1n}) \]

\[ U_2 = u(\text{Attrib}_{21}, \text{Attrib}_{22}, \ldots, \text{Attrib}_{2n}) \]

\[ U_3 = u(\text{Attrib}_{31}, \text{Attrib}_{32}, \ldots, \text{Attrib}_{3n}) \]

Resources and Constraints

Stated Choice
Revealed Choice
Demand
Utilization
McFadden’s Model

Experience

Memory
Motivation/Affect
Attitudes

Information
Perceptions/Beliefs
Process
Preferences

Attitudes
Stated Preferences

Stated Perceptions
Choice (Revealed Preferences)

Time and Dollar Constraints
Individual Decision Making Model

Experience/Affect

Information

Attribute Value
Attribute Value
Attribute Value
Attribute Value
Attribute Value

Preference/Choice Concordance

Patient Preferences

Physician Recommendation

Treatment Choice

Decision Quality Knowledge, Satisfaction, Conflict, Regret

Treatment Outcomes Functional Status, Quality of Life, Symptoms
What are the outcomes of interest: Informed and values-based decisions?

- Recognize a decision needs to be made
- Know choice alternatives and their features
- Understand that values affect decisions
- Be clear about option features that matter most
- Discuss values with their practitioner
- Become involved in preferred ways
Characteristics of Strong Measures of Patient Values

- Comprehensive in patient considerations
- Evidence for reliability and validity
- Feasible in a busy clinics or in diverse populations
- Appropriate for all educational backgrounds
- Related to recommendations and outcomes
Contributions of improved assessment of patient values and preferences?

- Clarification of individual differences in decision making
- Understanding of how preferences may be constructed over time
- Improved patient-centered care
- Strengthened patient/physician relationship
Methods of Measurement

- Utilities Elicitation
  - Standard Gamble
  - Time Trade-Off
  - Visual Analog Scale
  - Rating Scales
- Attitude Questions
- Conjoint Analysis
- Combination Approaches
Utilities

- Value between 0 and 1, where 0 represents the value of being dead and 1 the value of living with perfect health

- Represents patient’s subjective value for choice attribute, such as a health state or a treatment characteristic
Welcome to the Prostate Utilities Assessment Survey

Hello, I am the interviewer who you will be working with you on a study designed for newly diagnosed prostate cancer patients. During the next twenty minutes, I will ask you to make imaginary choices having to do with possible side effects from treatment. I want to make sure you understand that these are not real choices you will be making in the future, and that no one can predict whether or not you will actually have any of these problems.

Please click the arrow below to continue.
Now I want you to imagine something different. I want you to forget all of your real health problems, and imagine that you are in perfect health, except that you have urinary incontinence. This means that you are unable to control the flow of your urine. You may leak urine unexpectedly, and you may have to wear pads under your clothing. You may have an accident when you are doing something you enjoy, such as fishing, playing cards, or playing golf. There are treatments that can help some men with incontinence.
Standard Gamble

Prostate Utilities Assessment

Health State query for Incontinence
Visual Analog Scale

Imagine living the rest of your life with incontinence the way I just described it. If you had this type of incontinence, how would you rate your quality of life, compared to perfect health and death?

Click here to Answer the question

Send questions about this survey to
phb@northwestern.edu
Standard Gamble

Don't play the game

Live with incontinence

Choice

Play the game with 100 marbles

Perfect health (white marble)

Death (black marble)
### Standard Gamble

Please check the 'YES' column if you would play the game, or check the 'NO' column if you would not play the game.

<table>
<thead>
<tr>
<th>black marbles (death)</th>
<th>white marbles (perfect health)</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>100</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>100</td>
<td>0</td>
<td>✔</td>
<td></td>
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<tr>
<td>10</td>
<td>90</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>90</td>
<td>10</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>80</td>
<td>✔</td>
<td></td>
</tr>
</tbody>
</table>

Would you accept a **20** % chance of death and a **80** % chance of perfect health?

![Start Over button](start_over_button.png)
Example: Visual Analog Scale

If you had incontinence, how would you rate your quality of life?

Perfect Health

Death

The quality of life is 85% of perfect health.

Move the cursor over the scale and the level will change. Click to set your level. You can also click on the up or down arrows. When you are satisfied with your rating, click on "Done".
Advantages of Utilities

- Based on economic and psychological theory; meets assumptions of normative decision making
- Experimental task involving a choice
- Scores comparable across methods
- Useful in studies of health economics and policy
Limitations of Utilities

- Questionable reliability
- Logical inconsistencies within methods
- Limited evidence for validity
- Inconsistencies in scores across methods
- Not well accepted by patients
- Difficult for patients with low literacy and low numeracy
- Not related to treatment recommendations

Souchek et al., 2000
Attitude Measures

- Attitudes are defined as a psychological tendency that is expressed by evaluating a particular entity with some degree of favor or disfavor.

- Usual measurement is through ratings or rankings.

Eagly and Chaiken, 1996
13. How would you feel about losing all or some of your ability to have an erection?

☐ 1. I could not deal with any loss of my ability to have an erection

☒ 2. I could deal with having weaker erections or erections less often for a few months

☐ 3. I could deal with losing some ability to have an erection forever

☐ 4. I would accept any loss of erection, for any period of time, if it was necessary to treat my cancer
Evaluation of Attitude Measures

- Requires few assumptions about underlying choice processes
- Easy for participants
- Holistic approach
  - Valuation of an attribute as a whole
  - Does not allow evaluation of levels or different categories of an attribute
- Vulnerable to “halo” effects

Phillips, Johnson, Maddala, 2002
Bockenholt has suggested that using a nested approach to understanding value judgments.

Comparative judgments are integrated with absolute judgments.

Relative value and information about scale origin.
## Importance Ratings

<table>
<thead>
<tr>
<th>How important is...</th>
<th>Extremely Important</th>
<th>Very Important</th>
<th>Moderately Important</th>
<th>A Little Important</th>
<th>Not Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoiding a treatment that causes problems for my relationship with my spouse/partner</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Best Worst Scaling

Circle the concern that is most important to you in making your decision about your prostate cancer treatment:

- Important Relationships
- Urinary Function
- Responsibilities
- Survival
- Sexual Function
- Treatment Characteristics
- Important Relationships
- Self-esteem
Construct and Method Selection

- Ideally should be based on the purpose of the effort to understand preferences

- Cost analyses may require a different conceptual framework for understanding preferences and values and a different method for assessment than use of patient values in clinical decision making
Qualitative Approaches

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Literature Review

- Good starting place for well-studied conditions.
- To understand patient concerns for some conditions, you may need to focus on
  - Case studies
  - Clinical outcome studies
Expert Panel

- Clinicians can report on their own experience.
- Evaluate material identified in literature review.
- Other researchers can suggest approaches and important issues to consider.
Focus groups

- Used to identify group norms, impressions
- Usually $\leq 10$ participants
- Moderator must be experienced in group process.
- Helpful to match on ethnicity and gender.
- Useful in early stages of research to understand what are a group’s concerns.
Men discussing the positives and negatives of being tested for HIV.

Most of the participants were aware that the HIV antibody test was available. Some, however, expressed ambivalence about being tested:

“Get a checkup, to get out of worry and be tranquil.”

“The fear of knowing we have it. All of us, after we were married...we remain blind, wondering if we have it. To be blind, or to know?”

"Well, at this point in my life, I think it’s more psychological than anything else. It’s the knowledge that you cannot perform, and it’s that knowledge, I think, that’s more disturbing than maybe the actual fact. After all, it’s a capacity you’ve had all your life and then suddenly it’s gone."

- Focus group participant quoted in Bokhour et al (2001)
APPENDIX: PSYCHOLOGICAL IMPACT OF ERECTILE DYSFUNCTION, VERSION 1.0

Over the past 4 weeks... (Please check the response that fits best by marking the box)

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I am more irritable than I used to be</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. At times, I have felt so devastated by the performance of my penis that I wanted to die</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. My erectile dysfunction makes me feel like less of a man</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>4. I lack masculine confidence</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>5. I am easily frustrated by little things</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

Identifying issues of treatment regret

- FG and survey
- FG discussions identified 3 issues
  1. Definitiveness of tx – orchiectomy vs. biochemical castration
  2. Role in decision-making – passive vs. active
  3. Information needs – doctors seen as knowing it all but not necessarily sharing information
“Well, first of all, I don’t discuss it with nobody unless it’s more or less with the doctors, you know, . . . it’s just nothing I pitch around wherever I stop for conversation. But my wife, she’s active in everything I need, if there’s any help I need in any way, I usually go to her.”

“the only person really that really helped me a lot of course is my wife. Now, I’ve talked with my brother over the phone several times. He’s the one who I told you had prostate cancer for 15 years.”

“the support I have of course is from my wife and children. We haven’t talked about it publicly…since mine has been fairly minor, it’s been more of a psychological thing…I have support with my family, and my friends too, the ones that know.”

“I’ve discussed it with [my] golf buddies… A number of them have gone through similar situations, quite a few have. They had an operation in fact.”
Support for men with PCa on WW

Limited Support

“I have a lot of wonderful friends…and I am sure that I could call on them, but I don’t go around asking for help…I never have gone out and sought their support. I just don’t go around asking for support cause I’ve go cancer…”

“I’m in the Golden Age Kiwanis Club . . . the members don’t even know I have prostate cancer. I’ve kept it [to myself].”

“I don’t discuss [prostate cancer] with . . . others. I’m a rather private person and I don’t care about joining these support groups.”

Donald E. Bailey Jr., PhD, RN, Janet L. Stewart, PhD, RN, Merle H. Mishel, PhD, RN, FAAN. Watchful Waiting in Prostate Cancer: Where Can Older Men Find Support? Poster presented at the 8th annual Oncology Nursing Society research meeting.
Analysis methods

- Content analysis
- Ethnography
- Grounded theory
- Software
  - NVivo
  - Ethnograph
Inductive vs. deductive

- Inductive reasoning
  - is the process of arriving at a conclusion by examining facts or examples; **particular to general**. Example: There are tire tracks in the snow and a smell of gasoline in the air; therefore, I conclude that a motorized wheeled vehicle has been here recently.
Inductive vs. deductive reasoning

- Deductive reasoning
  - a type of thinking in which we begin with a rule and move to an example in order to draw a conclusion.
  - The process of reasoning from general principles to particular examples.
Critical Incident Reports

- Reports are written by “subject matter experts” – an experienced nurse re: what makes a good nurse for NCLEX; someone with good symptom control; a health care provider about a patient, etc.

- Data are collected and continuously evaluated until a category is “saturated” – you begin getting the same information from many respondents.
Critical Incident Report

- Specific examples aggregated to more general categories – a taxonomy.
- Usually have 2 taxonomies – effective and ineffective actions.
- Effective reports tell you what to include in a decision aid or intervention. Ineffective reports tell you what misinformation you need to dispel.
### Critical incident interview questions

<table>
<thead>
<tr>
<th>Form I</th>
<th>Form II</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Think about a time a nurse treated you with respect. When did this happen?</td>
<td>(1) Think about a time a nurse treated you without respect. When did this happen?</td>
</tr>
<tr>
<td>(2) What were the circumstances which led up to this event?</td>
<td>(2) What were the circumstances which led up to this event?</td>
</tr>
<tr>
<td>(3) What exactly did the nurse do?</td>
<td>(3) What exactly did the nurse do?</td>
</tr>
<tr>
<td>(4) How did you respond to the nurse?</td>
<td>(4) How did you respond to the nurse?</td>
</tr>
<tr>
<td>(5) How did the nurses' actions affect your behavior?</td>
<td>(5) How did the nurses' actions affect your behavior?</td>
</tr>
<tr>
<td>(6) What would have been helpful to you?</td>
<td></td>
</tr>
</tbody>
</table>
**Table 4.1  Tips for Writing Critical Incident Reports**

1. Concisely describe the situation, the action taken, and the outcome. Carefully decide what information is relevant to each event.
2. Describe what the apprentice or journeyman did (or failed to do) in that specific situation. Do not describe “types of things that people do” or general traits of effective or ineffective workers. The emphasis should be on what was observed, not on interpretation of the action.
3. Focus on the actions of a single person rather than those of a team.
4. Write events in the third person (he or she) and do not use personally identifying information. Use terms such as “the apprentice” and “the supervisor.” Even if you relate events that are things you did, please write them in the third person.
5. Write about actions you have taken or the actions of others that you have personally observed, not situations reported to you by someone else, because your recollection of these events will be the most vivid and accurate.

### Table 3: Example of useful critical incident

**Think of a time a nurse treated you well/not well**

'I was in the hospital two months ago. I was depressed about having AIDS and stabbed myself in the stomach.'

**What were the circumstances that led up to this event?**

'It was right after surgery and I was supposed to walk. I didn’t want to try. I just wanted to lay there.'

**What exactly did the nurse do?**

'The nurse got me up and put her arm around me and we walked down the hall. She talked with me about her children and then got me to talk about my children. She had a daughter...me too. She teased me about my boyfriend.'

**How did you respond to the nurse?**

'It was nice and pleasant. The nurse made me feel like I want to try. She gave me courage. It made my behaviour nicer, and I tried not to give her a bad time.'

**How did the nurse’s actions affect your behaviour?**

'I talked back to her. We were two persons on the same level. She didn’t treat me any differently than I treated her. We were the same. I did everything to make her job easier. Do everything you can to help them if they treat you good.'
Not useful CI reports

Table 4 Critical incident reports that were not useful

Example 1
*Think of a time that a nurse treated you well/not well*
‘They’re all OK. Nothing stands out. The nurses are fine. They’ve all been great. I can’t think of a specific example. They treat me good everyday. They help me with whatever I need. I feel good’

Example 2
*Think of a time that a nurse treated you well/not well*
‘The nurses are all good to me.’

*Exactly what did the nurse do?*
‘The nurses start conversations with me...they change my bed promptly and without asking, and they check to see that I have ice water. They help me with the things I need’

*How do you respond to the nurse?*
‘It gives me self-confidence. I realize that I’m not facing this alone and that they’re not afraid to shake my hand or touch me’
Data analysis

- Begins with writing reports in standard format.
- Read first incident. Classify it. Read next incident – same category or a new one?
- Keep reading and sorting incidents into categories.
- Additional experts perform same sorting procedure. Compare results – inter-rater reliability.
Validating taxonomies

- Resolve discrepancies between experts. Do some categories need to be collapsed or split into new categories?
- Draw random sample of incidents.
- Have new expert classify incidents into existing taxonomy.
- For health care-related applications – medical review as needed.
Cognitive interviews

- New measure/material development
- “Think-aloud” and verbal probing techniques
  - Understanding of questions
  - Reaction to the intervention materials or questions
  - May result in rewording/elimination/addition of questions/materials
Cognitive interviews

**Think aloud**

19. Selecting a treatment that allows me to meet my family responsibilities.

- □
- □
- □
- □
- □
- □

- Well, it depends on what you mean by family responsibilities. Do you mean money? Helping my wife with your grandkids? My wife says she’s OK with any treatment as long as I’m still alive.
### Verbal probes

- **Comprehension/Interpretation probe:** What does the term "outpatient" mean to you?

- **Paraphrasing:** Can you repeat the question I just asked in your own words?

- **Confidence judgment:** How sure are you that your health insurance covers drug and alcohol treatment?

- **Recall probe:** How do you remember that you went to the doctor five times in the past 12 months?

- **Specific probe:** Why do you think that cancer is the most serious health problem?

- **General probes:** How did you arrive at that answer? Was that easy or hard to answer? I noticed that you hesitated - tell me what you were thinking.

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Conjoint Analysis: An Introduction

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University of Kentucky College of Medicine

(31st Annual Meeting & Scientific Sessions of the Society of Behavioral Medicine, 2010)
Goals & Overview

- Provide a general overview of basic conjoint methods
- Discuss considerations in the development of a conjoint survey
- Review some examples of conjoint analyses in health decision making research
Conjoint Analysis (CA)

- A *decompositional* approach to understanding the attributes that influence decision making.

- Allows attributes to be evaluated in relation to each other, or "conjointly".

- Provides information about *individual decision-making, group decision-making, specific attributes, and preferred levels of products or services*.

- **Assumptions**
  - Each good or service is a bundle of potential attributes.
  - Each individual maintains a set of unique relative utilities for attribute levels.
  - Combining utilities for different attributes provides an individual's overall relative utility for a specific good or service.

(Phillips, Johnson & Maddala, 2002)
Conjoint Analysis: Historical Context

- Developed by psychologists (Luce & Tukey, 1964)
  - Subsequently adopted heavily in marketing research

- Modified for discrete choices (McFadden, 1974)
  - Expanded into broader policy influence/econometrics

- Additional applications in health decision making (Ryan)
  - Provider and patient decision making

- Integrating into clinical care to provide values clarification exercise for informed decision making (Hawley)
Conjoint Use in Health Research

- Provider decision influences
- Patient decision influences
- Patient satisfaction
- Willingness to pay for services
- Comparison of insurance plan options
- Technology assessment
- Anticipated uptake of services/interventions
- Preference elicitation to facilitate informed decision making
Strengths of Conjoint Analysis – I

- CA more closely approximates real healthcare choices
- CA obtains more information from each subject
- CA makes subjects think about trade-offs and thoroughly examine preferences
- Allows for the valuation of both the product and its attributes
- CA is less impacted by external influences like social desirability or universally high ratings.
  - Importance of attributes is estimated based on actual decisions, not participant ratings

(Sattler & Hensel-Börner, 2007)
Strengths of Conjoint Analysis – II

- CA is more sensitive to changes in attribute levels
- CA is less time-intensive than time trade-off (TTO) or standard gamble (SG) approaches to eliciting utilities
- CA places less quantitative burden on participation numeracy skills than TT) or SG approaches
- CA data can be provided with other self-explicated data or other sources of information to develop better models of behavior
- CA has potential to serve as a values clarification – preference elicitation strategy in a decision aid.

(Sattler & Hensel-Börner, 2007)
Limitations of Conjoint Analysis

1) Respondent burden is heavier than other survey approaches
   • Reading and organizing information
   • Making a judgment

2) Inability to evaluate a large number of attributes and levels
   • Expanding attributes and levels quickly increases the number of scenarios needed to estimate importances and part worths

3) Analysis of discrete choice data can be quite complex and there is ample debate regarding the appropriateness of some of the methods of estimating these models

4) Some of the previously noted strengths are predominantly theoretical and lack consistent evidence

(Sattler & Hensel-Börner, 2007)
Types of Conjoint

- **Full-profile/Full-concept**
  - Ranking or rating

- **Choice-based Conjoint**
  - Making discrete choices from a number of options

- **Adaptive Conjoint**
  - Using choices to refine options and elicit utilities more efficiently
## Ranking

- Participant reviews all possible scenarios, vignettes and provides a rank ordering of most preferred to least preferred vignette.

## Rating

The patient is a 13-year-old girl and is not sexually active. The vaccine is effective against HPV types that cause both cervical cancer and genital warts. Efficacy of the vaccine is 80%. The American College of Obstetricians and Gynecologists (ACOG) has recommended this vaccine be given.

<table>
<thead>
<tr>
<th>Rating</th>
<th>0</th>
<th>10</th>
<th>20</th>
<th>40</th>
<th>50</th>
<th>70</th>
<th>80</th>
<th>100</th>
</tr>
</thead>
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</tbody>
</table>
Choice-based Conjoint (CBC)

- Examines discrete choices from a number of presented options

<table>
<thead>
<tr>
<th>Attributes</th>
<th>Treatment A</th>
<th>Treatment B</th>
<th>No Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Pain</td>
<td>Well Controlled</td>
<td>Fully Controlled</td>
<td>Poorly Controlled</td>
</tr>
<tr>
<td>Heart Attack Risk</td>
<td>10 in 10,000</td>
<td>30 in 10,000</td>
<td>5 in 10,000</td>
</tr>
<tr>
<td>Personal Cost</td>
<td>$100 per month</td>
<td>$250 per month</td>
<td>$0 per month</td>
</tr>
</tbody>
</table>

Please indicate your preferred treatment:

- [ ] Prefer Treatment A
- [ ] Prefer Treatment B
- [ ] Prefer No Treatment
Adaptive Conjoint Analysis (ACA)

- Using choices to refine options and elicit utilities for a broader range of attributes more efficiently
- Utilizes some initial self-explicated ratings
- Iteratively presents choice options that provide the most information about utilities
Selecting Between Conjoint Types

- **Traditional Full Profile Conjoint**
  - Attributes six or fewer
  - Small sample size (less than about 100).

- **Adaptive Conjoint Analysis (ACA)**
  - Too many attributes to study using the other techniques.
  - Considered more engaging than other approaches.

- **Choice-Based Conjoint (CBC)**:
  - Best real-world model
  - Requires larger sample sizes to stabilize estimates.
  - Attributes six or fewer
Conjoint Methodology
Conjoint Basics

1. Accurate definition of attributes and levels
2. Appropriate selection of choice formats
3. Selection of an efficient experimental design
4. Careful and appropriate statistical analysis

(Johnson, Hauber, & Paulos, 2009)
1. Attributes and Levels

- Key elements of the conjoint survey

- Attributes are the “factors” being considered

- Levels represent the different aspects of the attributes

- Efficacy
  - 50%
  - 75%
  - 100%

- Route of Administration
  - Oral pill
  - Anal suppository
  - Injection/Shot

- Duration of Coverage
  - 2 years
  - 5 years
  - 10 years
Considerations: Attributes

- What is an appropriate number of attributes?
  - No magic number, depends on design
  - More attributes create more respondent burden
  - Attributes must make choice meaningful and address specified research questions

- Labeled vs. Unlabeled Attributes

- Forced choice vs. No Option
Considerations: Levels (of Attributes)

- **Number of levels**
  - More levels make experimental design more difficult, try to keep the number of levels between 2-4
  - Do not need every level possible for an attribute
  - Uneven number of levels can have cognitive effects

- **Combinations of levels**
  - Don’t have to be technologically feasible, just believable
  - Include decision/policy-relevant ranges (for example, risk range should include expected risks, cost range should include expected cost)
Potential Biases

- **Hypothetical bias**
  - Concern that individuals respond differently under hypothetical conditions than they do in real situations
  - CA lacks the consequences of actual choices

- **Several possible responding biases**
  - Simplification bias, dominant responding (no variance)

- **Solutions**
  - Design realistic and efficient (brief) conjoint surveys
  - Integrate checks for attention and consistency
2. Choice Formats

- Rankings
- Ratings
- Discrete Choices
- Mixed
  - Pairwise Trade-off
Ranking Format

- **Ranking (Not recommended)**
  - Burdensome as number of options increases
  - Harder to get data about “opt-out”
  - Interior rankings may not be reliable
  - No information about strength of preferences

<table>
<thead>
<tr>
<th>Option</th>
<th>RAM</th>
<th>Screen Size</th>
<th>Price</th>
<th>Rank (1 to 8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2 GB</td>
<td>12 in.</td>
<td>$1500</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>4 GB</td>
<td>14 in.</td>
<td>$1000</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>4 GB</td>
<td>12 in.</td>
<td>$1500</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>2 GB</td>
<td>14 in.</td>
<td>$1500</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>2 GB</td>
<td>12 in.</td>
<td>$1000</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>4 GB</td>
<td>14 in.</td>
<td>$1500</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>4 GB</td>
<td>12 in.</td>
<td>$1000</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>2 GB</td>
<td>14 in.</td>
<td>$1000</td>
<td></td>
</tr>
</tbody>
</table>
Rating Format

- **Rating**

  - Provides information on strength of preferences, can be transformed into ranking or choice

  (Johnson et al. 2009)
Choice-Based Formats

- Most commonly-employed approach
- Most consistent with discrete choice made by consumers regarding products or services
- Dichotomous data

If you were in the market to buy a new PC today and these were your only options, which would you choose?

- Dell
  - 2.8 GHz Processor
  - $1,500
- IBM
  - 3 GHz Processor
  - $1,250
- Compaq
  - 3.2 GHz Processor
  - $1,750
- NONE: I wouldn’t choose any of these.

Choose by clicking one of the buttons above.
Mixed

- **Pairwise Trade-off**
  - Parallels real choice scenario by comparing two products or services
  - Maintains ratings-level data for analysis flexibility

<table>
<thead>
<tr>
<th>Which laptop computer would you rather purchase?</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 GHz processor</td>
</tr>
<tr>
<td>7-hour battery life $1,250</td>
</tr>
<tr>
<td>1 Strongly prefer left</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3 Strongly prefer left</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
</tbody>
</table>


3. Experimental Designs

- Experimental design describes the number and specific combinations of levels that will be presented to respondents.

- (usually) the goal is to identify a minimal set of cards or scenarios that will allow estimation of all desired effects.

- Efficient tradeoff questions lead to precise estimates of respondents' preferences.
Designs

- Full factorial
  - All combinations of attributes and levels
  - Usually not feasible

- Fractional factorial designs
  - Published design tables
  - Software programs
Hold-out Cards/Scenarios

- Cases that are included in the survey but do not contribute to the model.

- Used as a form of cross-validation.

- After model is developed, responses to the hold-out cases are estimated (predicted) using the model.

- Estimates are then correlated with actual responses to provide an index of validity.
4. Statistical Analyses

- Descriptive information/Average responses
- Importances
- Part worths
- Segmentation possibilities
Exploratory Analyses

- Same precautionary inspection of data is needed in CA as any other statistical analysis

- Distributional properties of participant responses on each vignette
  - Mean ratings on each vignette, in particular

- Frequencies and other visual displays can be very informative
Generate Preferences

- Software generates attribute importance scores and part worth utilities
  - OLS used to calculate the utilities
    - Appropriate when data are interval scaled
    - Other options when data are rank ordered
    - More complex approaches available for discrete choice
  - Calculated for each respondent, then averaged
Attribute Importance Value

- The relative importance of each attribute.

  - the difference each attribute could make in the total utility of a product = the range in the attribute’s utility values.

  - Calculate percentages from relative ranges, obtaining a set of attribute importance values that add to 100 percent
Part worth Utilities

- Relative importance of levels within each attribute.
  - When using effects coding, utilities are scaled to sum to zero within each attribute.
  - Negative part worths do not necessarily mean disfavor, but may simply indicate relatively less preference compared to other levels within the attribute.
  - Are interval scale data, cannot be compared across attributes.
  - Provides information about participant preferences relative to other levels.
Questions and Examples
Conjoint Analysis Examples

- **Example 1**
  - Gynecologist Attitudes toward HPV Vaccination

- **Example 2**
  - Conjoint Analysis to Facilitate Shared and Informed Decision Making Regarding Colorectal Cancer Screening
Gynecologist Attitudes toward HPV Vaccination

- Conjoint survey of Fellows of American College of Obstetricians and Gynecologists (N = 181)

- Research Questions:
  - What factors influence HPV vaccination acceptability?
  - Are there demographic characteristics associated with these influences?

(Raley, Followwill, Zimet, and Ault, 2004)
Attitudes toward HPV Vaccination

- Attributes & Levels
  - ACOG Recommendation (2)
    - yes vs. no
  - Vaccine Efficacy (2)
    - 50% vs. 80%
  - Patient Age at Administration (3)
    - 13, 17, 22
  - Disease Target (3)
    - Cervical Cancer, Genital Warts, Both

- 13 scenarios developed to assess the importance of these attributes and levels in vaccine acceptability

- Employed a rating scale approach

Scenario 1:
The patient is a 13-year-old girl and is not sexually active. The vaccine is effective against HPV types that cause both cervical cancer and genital warts. Efficacy of the vaccine is 80%. The American College of Obstetricians and Gynecologists (ACOG) has recommended this vaccine be given.

(Raley et al., 2004)
Results

- Across all 13 scenarios, the mean acceptance of vaccination was 79 ± 16.6 (scale of 0 to 100), indicating generally favorable acceptance.

- No sociodemographic variables were associated with scenario ratings (aim 2).

(Raley et al. , 2004)
Results: Importance & Part worths

Influences on Vaccine Acceptability

- ACOG (Yes)
- Efficacy (80%)
- Patient Age (13)
- Target

(Raley et al., 2004)
Conclusions

- Professional organization endorsement was most influential, followed by efficacy, age, and target.

- Participants were disinclined to administer to 13 year olds.

- Highest acceptance was associated with ACOG approval, high efficacy, and administered to 22 year-olds for the purpose of preventing both cervical cancer and genital warts.

(Raley et al., 2004)
Colorectal Cancer Screening Decision Tool

- Evaluating a Preference-based Intervention for Increasing CRC Screening in the VA Healthcare System (VA IIR-06-205-Hawley)

- A Preference-tailored CRC Screening Intervention in Diverse Primary Care Settings (R01 CA131041-Hawley)

(Courtesy Sarah T. Hawley, Ph.D.)
CRC Screening Decision Tool

- Helping eligible patients clarify their CRC screening preferences will lead to increased adherence.

- Preference clarification will increase the patient's knowledge and awareness of the factors that are important to him or her in getting screened for CRC.

- Patients will be better prepared to participate in an informed decision making process with their provider.

- Improving informed decision making will lead to reduced decisional conflict, a greater intention to get screened and, eventually, to better adherence with screening.

(Hawley: R01 CA131041)
Specific aims:

1) To test the effectiveness of a preference-tailored (PT) vs. standard information (SI) intervention for increasing primary care patient's CRC screening adherence in a randomized controlled trial at two locations.

2) To assess the impact of the intervention on informed decision making, knowledge and attitudes toward screening, decisional outcomes, and intention to get screened; and

3) To conduct a cost effectiveness analysis of the PT intervention for increasing CRC screening.

(Hawley: R01 CA131041)
DECIDER GUIDER

Option 1 is a test with these qualities:
- test every 5-10 years
- follow up tests needed
- I strongly prefer Option 1

Option 2 is a test with these qualities:
- yearly testing
- no follow up tests
- I strongly prefer Option 2

(Courtesy Sarah T. Hawley, Ph.D.)
Conjoint Integration

- Conjoint used to help educate patients and help them clarify preferences

- Conjoint provides a preference-sensitive recommendation

- Recommendation is shared between patient and provider to facilitate shared and informed decision making regarding CRC screening
Conjoint Analysis: Summary

- Although developed by psychologists, the method has experienced its greatest use in marketing research.

- Conjoint is an intriguing decompositional approach to understanding patient preferences that warrants greater consideration in behavioral medicine.

- Although it may engender significant respondent burden, it can provide unique information about individual and group decision making and has many distinct advantages over other preference elicitation approaches.
Conjoint Analysis Summary II

- This introduction has only skimmed the surface of conjoint basics.

- There are several tools and support systems to help individuals develop the skills and resources necessary to conduct CAs.
Questions
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Fax: (859) 323-5350
Email: jamie.studts@uky.edu
Psychometric Evaluation of a Patient Preferences Index

Laura P. Sands, PhD
Purdue University
lsands@purdue.edu
## Psychometric Evaluation of Instruments

<table>
<thead>
<tr>
<th>Method</th>
<th>What it Assesses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reliability</strong></td>
<td></td>
</tr>
<tr>
<td>Internal consistency</td>
<td>Consistency between responses</td>
</tr>
<tr>
<td>Test-retest</td>
<td>Consistency in responses over time</td>
</tr>
<tr>
<td><strong>Validity</strong></td>
<td></td>
</tr>
<tr>
<td>Face</td>
<td>Evidence the correct concept is being measured</td>
</tr>
<tr>
<td>Content validity</td>
<td>Evidence for adequacy of coverage</td>
</tr>
<tr>
<td>Criterion-related</td>
<td>Establish an association between scores and some external criterion</td>
</tr>
<tr>
<td>Construct validity</td>
<td>Establishes the construct the instrument is measuring</td>
</tr>
</tbody>
</table>
## Reliability: Internal Consistency

<table>
<thead>
<tr>
<th>Interpretation</th>
<th>The consistency of responses within a scale or within a subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statistical Method</td>
<td>Cronbach’s alpha ((\alpha)) is the most common method. It is based on the average correlation over items weighted by variances</td>
</tr>
<tr>
<td>Interpretation</td>
<td>It is the percent of variance that the current scale explains of the unidimensional underlying construct being measured</td>
</tr>
<tr>
<td>Acceptable values</td>
<td>Values range from 0-1.0 with higher scores reflecting more accurate measure of the underlying trait. Values below .70 suggest a need for evaluation of each item within the scale</td>
</tr>
</tbody>
</table>
Improving Internal Consistency

1) Increase the number of items within a scale to increases $\alpha$.

Ex. If one were to increase the number of items in a subscale with an $\alpha$ of .6 by 3 times, the reliability would become 0.82 (Spearman- Brown formula)

2) Items that have a low correlation with the overall scale should be eliminated.

Ex. The VIBES Subscale for sexual function has includes items about sexual function, interest, and fertility. It appears that fertility is measuring a different underlying concepts than the sexual functioning items
Improving Reliability By Deleting Items

The addition of items with low item-scale correlations reduces the reliability of a scale:

Sexual function scale of VIBES:

<table>
<thead>
<tr>
<th>Item</th>
<th>Subscale α</th>
<th>Item-total correlation</th>
<th>α if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual Function:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>+ Maintain erection</td>
<td>.85</td>
<td>.81</td>
<td>.75</td>
</tr>
<tr>
<td>- Decrease sexual interest</td>
<td></td>
<td>.81</td>
<td>.75</td>
</tr>
<tr>
<td>and desire</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>+ Maintain active sex life</td>
<td></td>
<td>.84</td>
<td>.73</td>
</tr>
<tr>
<td>- Causes loss of fertility</td>
<td></td>
<td>.33</td>
<td>.94</td>
</tr>
<tr>
<td>Interpretation</td>
<td>The stability in responses across assessment occasions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>-------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experimental Method</td>
<td>The same instrument is administered twice to the same sample on two occasions usually 1-2 weeks or up to one month apart</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statistical Method</td>
<td>Intraclass reliability coefficient for continuous valued measures, kappa for discrete valued measures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acceptable values</td>
<td>Values range from -1.0 - 1.0 with higher scores reflecting more accurate measure of the underlying trait. Values below .60 suggest low consistency and potential future difficulty in detecting differences due to real effects</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Improving Test-Retest Reliability

1) Reduce the potential for administration style to affect responses.

   Interviewers may inadvertently introduce positive or negative cues that may affect subjects’ responses

2) Provide practice items to improve respondent’s understanding of how to express their preferences.

   When using utilities measurements subjects may order their preferences for states illogically. (Med Care 2000:38(9S)138-) It is important to acquaint the subject with all types of response formats that they must use
Improving Test-Retest Reliability

The timing of test-retest assessments should consider whether the patients are in a stable or transient phase of preferences for treatment.

Stable phase: test–retest interval may be 2 weeks apart

Unstable phase: test-retest interval should be within days and should not occur between events that may affect preferences
Measurement of Test-Retest Reliability for Utility Measurements

1) Compute the intraclass correlation coefficient
   Utilities can be considered to be continuously valued. However, research has demonstrated that >80% of preference ratings take on approximately 3 values: 1.0, .9, or .5, suggesting that a more appropriate statistical measure may be Cohen’s kappa. (Med Care 2000:38(9S);138-)

2) Compute the mean absolute difference in responses
   Patients were asked to imagine a treatment that would permit them to live in perfect physical and mental health but would reduce their life expectancy. Patients were asked to state how many months out of 10 years that they were willing to give up for such a treatment. (JGIM 1999:14;357-)

   One-day test-retest reliability showed a mean change of 2.04 months (95% CI=-4.86 - .78)
## Validity: Face

<table>
<thead>
<tr>
<th>Interpretation</th>
<th>Determination that the instrument is measuring the construct of interest</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assessment Method</strong></td>
<td>Prior to instrument development, focus groups can inform the content of the assessment instrument. After the development of the instrument cognitive interviews can be used to assess patients’ reaction and understanding of the content of the questionnaire</td>
</tr>
<tr>
<td><strong>Statistical Method</strong></td>
<td>No specific statistical method is associated with documenting face validity</td>
</tr>
<tr>
<td><strong>Population considerations</strong></td>
<td>The face validity of an instrument may vary across patient populations</td>
</tr>
</tbody>
</table>
Face Validity: Determining Domains Related to Patients’ Preferences

- 75 men diagnosed with localized prostate cancer recruited for participation in focus groups
- Thirteen groups conducted; Each was homogenous in ethnicity (i.e., African American, Caucasian American) and primary treatment (i.e., radical prostatectomy, brachytherapy, external beam radiation therapy, watchful waiting)
- Two experienced moderators were matched to the groups by gender and ethnicity
- Major questions posed to focus group participants:
  - What did you know about prostate cancer before diagnosis?
  - Tell me about making a decision about care for prostate cancer.
  - How did your decision impact your life?
Face Validity
Results From Focus Groups:
Domains Related to Patients’ Preferences

- **Survival**
  - Anxiety about Mortality
  - Recurrence Concerns
  - Cancer Removal
  - Prolonging Survival
  - Risk of Death

- **Treatment Procedure**
  - Characteristics
  - Invasiveness
  - Convenience

- **Pain/Discomfort**
  - Hot Flashes
  - Weight Gain
  - Skin Changes

- **Other Symptoms**
  - Self-Esteem
    - Self-Image
    - Body-Image
    - Masculinity

- **Relationships**
  - Spouse/Partner
  - Children
  - Friends

- **Responsibilities**
  - Work
  - Caregiving
  - Family

- **Sexual Function**
Methods for Improving Face Validity

1) Begin with a strong theoretical/conceptual framework that is informed by prior evidence.

2) Refine the conceptual framework using focus groups representative of the population of interest.

3) Use cognitive interviews when pilot testing the questionnaire. Ask subjects to explain what the question is asking.

4) Prior to using existing questionnaires pilot test the questionnaire on a representative sample. Use cognitive interviews to assess the relevance of the existing questionnaire to the situation of interest.
### Validity: Content

<table>
<thead>
<tr>
<th>Interpretation</th>
<th>Determining the adequacy of coverage of the instrument</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experimental Method</td>
<td>Experts in the area judge whether the instrument captures all domains of the construct of interest</td>
</tr>
<tr>
<td>Statistical Method</td>
<td>Though rarely reported, the Content Validity Index or the Content Validity Ratio indicates the extent of expert agreement.</td>
</tr>
<tr>
<td>Determination of Experts</td>
<td>Choose a panel of experts that informs rather than limits your interpretation of the breadth of your construct.</td>
</tr>
</tbody>
</table>
Content Validity: Determining Domains that Influence Preferences

The content validity of the instrument was developed by appraising existing research on prostate cancer treatment regarding:

- outcomes,
- decision models,
- utility elicitation.

Qualitative studies using key informants were conducted to clarify and expand the concepts revealed by research.

- nurses
- urologists
- radiation oncologists
- patient advocates

Interviews revealed clinicians have specific perceptions which are matched in part, but not entirely, by patient views.
Content Validity: Preferences for Prostate Cancer Treatment

Domains that were considered were, in part, influenced by prior research by Knight and others who found significant outcome differences between treatments. Negative outcomes included the following:

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Prostatectomy</th>
<th>Radiation/Hormonal</th>
<th>Watchful Waiting</th>
</tr>
</thead>
<tbody>
<tr>
<td>incontinence</td>
<td>√</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>sexual interest</td>
<td>-</td>
<td>√</td>
<td>-</td>
</tr>
<tr>
<td>sexual function</td>
<td>-</td>
<td>√</td>
<td>-</td>
</tr>
<tr>
<td>hot flashes</td>
<td>-</td>
<td>√</td>
<td>-</td>
</tr>
</tbody>
</table>
Methods for Improving Content Validity

Begin with a thorough literature review. Ensure the breadth of the literature review by searching on MeSH terms in addition to self-generated text terms.

Results of Literature Review: Domains to be Considered when Measuring Preferences for Prostate Cancer Treatment

- **Urologic**
  - e.g., Avoiding a treatment that causes leaking urine

- **Sexual**
  - e.g., Selecting a treatment that allows me to keep normal bowel function.

- **Bowel**
  - e.g., Selecting a treatment that allows me to keep normal bowel function.

- **Anxiety**
  - e.g., Selecting a treatment that makes me feel good about myself.

- **Other**
## Validity: Criterion

<table>
<thead>
<tr>
<th>Interpretation</th>
<th>The association between the construct and some external criterion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experimental Methods</td>
<td>Concurrent validity is usually measured on one occasion during which both the validation and construct tools are administered. Predictive validity requires that the construct is measured first and criterion is measured later</td>
</tr>
<tr>
<td>Statistical Method</td>
<td>Tests of association are used to assess construct validity such as a Pearson r for continuous valued scale scores, or Chi-square for categorical scale scores.</td>
</tr>
<tr>
<td>Criteria for assessment</td>
<td>Depends upon the overlap in concepts measured by the two instruments</td>
</tr>
</tbody>
</table>
Criterion Validity: Concurrent Validity of Preferences and Coping

Sexual Function Subscale:
+ Maintain erection
- Decrease sexual interest and desire
+ Maintain active sex life
- Causes loss of fertility

Correlation between VIBES Sexual Function subscale and Coping Scores Subscale

<table>
<thead>
<tr>
<th>VIBES subscale</th>
<th>n</th>
<th>Pearson’s correlation</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual function</td>
<td>393</td>
<td>0.56</td>
<td>&lt;0.0001</td>
</tr>
</tbody>
</table>

How well can I cope with:
Problems with erections, ejaculation, fertility, sexual interest and desire
Criterion Validity: Concurrent Validity of Preferences
Subscales and Time Trade-Off Utilities

Subscale scores will be compared with responses to Time Trade-Off responses:

e.g., Scores on the Urinary function subscale will be compared with responses to questions such as:

If you could have one or the other, which would you rather have?

a. Live the next 10 years with your current urine troubles, then die (give up no time)
b. Live the next 9 years with no urine troubles, then die (give up 1 year of life)
Predictive Validity: Assessing the Association Between Patients Preferences for Treatment and Eventual Choice

What should preferences for a preventive or treatment intervention predict?

- Preferences about a preventive or treatment intervention before a choice is made should predict the **intervention choice**
- Preferences should be **concordant with treatment outcomes**
- Preferences should also predict **treatment satisfaction**
Comments on Assessing Criterion Related Validity

It is difficult to assess criterion related validity because for predictive validity:
- it is difficult to follow patients to the end-point associated with the preference measure
- factors other than preferences influence the endpoint

and for concurrent validity:
- if a validated measure exists that assesses the same construct, then there is little reason to design a new instrument
## Validity: Construct

<table>
<thead>
<tr>
<th>Interpretation</th>
<th>Establishes the ability of the instrument to measure the construct and to distinguish varying levels of the presence of that construct</th>
</tr>
</thead>
</table>
| Experimental Methods | 1) Collection of data from many subjects from the patient population of interest to determine latent trait(s) underlying the assessment instrument.  
2) Collection of data from two groups known to vary on the construct (known-groups technique). |
| Statistical Methods | 1) A statistical method to explain variability in responses (e.g. factor analysis, component analysis).  
2) A statistical method to detect differences between groups (e.g. t-test) |
Construct Validity: Assessing the Dimensions of the Construct

**Exploratory Factor Analysis:**
Such methods allow the researcher to explore the number and nature of underlying dimensions within an instrument.

EFA does not take into account conceptual background work involved in creating scale items.

**Confirmatory Factor Analysis:**
Such methods consider the underlying concepts used to generate items included in an instrument and begin with a hypothesized set of factors.

EFA is important for testing whether hypothesized dimensions exist.
Construct Validity: Using the Known-Groups Technique

Two groups that should differ in subscale responses are those that choose to undergo treatment versus those who do not choose to undergo treatment:

Higher scores reflect greater importance in forming preferences.
Improving Construct Validity

1. Instrument development should begin with a clearly defined construct that is not too complex.

2. The theoretical/conceptual framework that describes your concept will help:
   a. Determine which groups should have different values for the concept.
   b. Determine the number of expected dimensions of your concept when using a variance reduction technique such as principle components analysis. Do not let the number of dimensions of your instrument be driven purely by empirical evidence.
Without evidence of reliability and validity, it is difficult to rule out the possibility that systematic bias or random variation are influencing results.
QUESTIONS
THANK YOU!